

SUMMARY OF ADVISORY COMMITTEE MEETING
Virginia Early Hearing Detection and Intervention Program
Virginia Department of Health
September 8, 2006
DRAFT

The following persons attended the meeting of the Virginia Early Hearing Detection and Intervention (EHDI) Program Advisory Committee: Frank Aiello, Barbara Allen, Jeannine Beden, Bob Boyle, Mark Campano, Craig Derkay, Darlene Donnelly, Leslie Ellwood, Sally Frasier, Nancy Ford, Ruth Frierson, Fredia Helbert, Ann Hughes, Jennifer Hutson, Claire Jacobson, Loucendia Lambert, Sue Lau, Dan Montero, Stephanie Moody, Casey Morehouse, Debbie Pfeiffer, Beth Tolley, Susan Ward, Dana Yarbrough, Pat Dewey.

Announcements and Updates

- Dr. Ellwood announced that he will be retiring from Kaiser in November. He will continue to serve on the Advisory Committee as the AAP Chapter Champion, but will no longer represent the Virginia Association of Health Plans. He is pursuing a replacement from that organization.
- Dana Yarbrough announced that Parent to Parent of Virginia and Medical Home Plus, Inc. have created the Virginia Integrated Network of Family Organizations (VA-INFO). To meet the need for access to a source of comprehensive, up-to-date information regarding available resources and programs, as well as effective referral and advocacy support to link families and providers to these resources for parents of children with disabilities and special health care needs, a mini grant from the Office of Children and Family at the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services and a 3-year grant from the US Health and Human Services: Centers for Medicare and Medicaid Services have been received to create the VA-INFO statewide family support coalition and Virginia's Family to Family Health Information and Education Center called the VA-INFO Center. The VA-INFO Center will provide youth and parents of children with special needs, including those with behavioral and mental health needs 1) one place to call to get information and training on the various service delivery systems statewide that support children and youth with special needs and their families; 2) referrals to supports and services in their area; 3) parent to parent peer support; and, 4) annual family support conference and other training opportunities. The VA-INFO coalition meets monthly in the Richmond area, bringing together youth and families who have children with special needs, representatives from state agencies, community-based organizations and disability specific support groups from across the Commonwealth to talk about the issues facing families, to network and collaborate, to inform policymakers of issues, and to develop training materials to educate parents on the service delivery system and other topics of interest to them. To join the VA-INFO coalition, learn more about the VA-INFO Center, or to get assistance from the Center, call (877) 264-8366 or visit www.medhomeplus.org.
- Mark Campano announced that the Virginia Deaf Blind Project held the first video conference with families. This was held from 7-8 pm at four sites around Virginia and was part of a needs assessment project. The conference was a success; program staff received a lot of input from the parents. Families have asked for this to be an ongoing interaction and are asking for meetings at least once a month.
- Fredia Helbert announced that she has assumed the Vice President of Audiology position for the Speech-Language-Hearing Association of Virginia (SHAV). Ann Hughes and Pat Dewey will work with her to support a speaker for the annual SHAV conference, spring 2007, as part of ongoing education initiative for audiologists statewide.
- Dan Montero reported that plans are moving forward on the proposed oral school in the Tidewater area. The planning group is considering the CASTLE model from University of North Carolina at

Chapel Hill, which is dedicated to providing quality auditory-oral early intervention and preschool services to children who are deaf or hard of hearing and their families.

- Beth Tolley, in response to a question about the status of the Part C system, reported on the new federal reporting requirements. The Office of Special Education Programs (OSEP) now requires an annual state performance plan. This plan includes outcome measures for federal requirements such as timely evaluations and services in natural environments as well as progress in knowledge and skills for children receiving services. One of the requirements is to monitor all localities. Therefore, each one will have to have chart reviews. Part C staff will be going to all 40 locations to verify the reported data. Also, the provision of services is changing due to new information about evidence-based practice. The new model is one where the parent is the therapist. Professionals train the parent to incorporate activities in everyday interactions with the child.
- Lou Lambert told the group about a call from a parent who is deaf. The parent was upset about the letter she received from the EHDI Program. The parent felt that the letter implied that hearing loss is a “problem”; neither she nor the deaf community feels that a child who is deaf is or has a problem. Lou Lambert attended a deaf luncheon group to ask for feedback on the parent letters. Anne Hughes agreed to help with the rewording of the letters.

Report from Virginia Department of Health

- VDH has received the notice of grant award for year two of the Health Resources and Services Administration grant. The amount is \$125,000. The focus in year 2 of the grant will be supporting the second follow-up position, establishment of the parent guide program, maintaining the hearing aid bank, continued training for audiologists and early intervention providers, travel to the National EHDI Conference.
- The Virginia Hearing Aid Loan Bank continues its good work. The total number of children receiving loaners as of the end of June is 47. Eighty-three aids, 11 binaural FM systems, and 1 monaural FM system have been loaned. Three children have received both hearing aids and FM systems; two children have received two sets of aids. There have been two losses; in both cases the families have paid the \$100, as per the signed loaner agreement. Twenty-four audiologists have participated.
- Claire Jacobson has convened a Work Group to revise the audiology assessment protocols. The group, comprised of eight Virginia audiologists, will meet at JMU for two days in late September. They will review the draft Joint Committee on Infant Hearing (JCIH) Position Statement for recommended changes in risk indicators and the focus on new technology; however the final protocols document will have to wait until the new position statement is published. Once the group has completed its work, the Advisory Committee will be asked to approve it. VDH staff will then format the document and obtain final VDH approval. The protocol documents are considered VDH guidance documents.
- Nancy Ford gave an update on the VISITS redesign project. The CDC-EHDI cooperative agreement provided 3 year funding for the redesign of VISITS. Work began July 2005 and the project is on target. The new system will do what the old system did but will expand to link with Care Connection to help with harder level follow up and finding children. It also will include an automatic referral to Part C- Early Intervention from both Virginia CARES and EHDI. Future plans are to link with the childhood lead poisoning prevention database. The 2006 General Assembly passed legislation that allows hospitals to see demographic information entered into VISITS by other hospitals. This will allow use of the Birth Certificate information as a basis for the infant record and help decrease duplicate records in the system.
- Pat Dewey reported that several parents had been invited to present information about national organizations with which they are affiliated. Today, Jennifer Hutson will discuss Hands & Voices. At the December meeting, Jackie Meeks (who serves on this committee) will discuss Alexander Graham Bell Association .

Hands and Voices

Jennifer Hutson presented information on a new parent group called Hands and Voices. This is a non-profit, parent driven, parent/professional collaborative group that provides support to the families of deaf and hard of hearing children. It is unbiased towards communication modes and methods. It was decided to have one organization representing all deaf people without bias around communication modes or methodology. Member families communicate orally, with signs, with cues, or combined methods. Jennifer and another parent, Missy Colley, are forming a chapter in Virginia.

Update from Partnership for People with Disabilities

Ann Hughes gave an update on the training and education activities conducted under the contract with VDH and supported by grant funds. The following have been accomplished:

- offered on-line courses for early intervention providers in sign language and service provision for children with hearing loss; 3 providers took "Facilitating Outcomes" and 5 took the "Intro to ASL";
- offered a one-hour, evening audio teleconference offered for primary medical care providers, co-sponsored with the American Academy of Pediatrics (a second had to be cancelled due to lack of enrollees);
- initiated a update and revision of the resource list section of the Information for Parent of Children with Hearing Loss, Virginia's Resource Guide for Parents

Ann Hughes also reported on the parent guide project. The work group met on August 16 and finalized the plans for the program, which will be called Virginia Guide By Your Side (GBYS). Partnership for People with Disabilities will manage the program under the contract with VDH EHDI; HRSA grant funds are supporting the project for the first year. The committee reviewed several models before choosing the GBYS model. Dana Yarbrough is Project Coordinator for the Virginia GBYS program; Jennifer Hutson will be the Parent Coordinator. The applications to become a parent guide were sent out statewide; 24 applications were received. Interviews will be scheduled the week of September 11. Training will be provided for the selected applicants Oct 13-14, 2006. Jennifer Hutson, Dana Yarbrough, and Ann Hughes will work on updating the resource guide for use by the families. The GBYS program is a product of the national organization, Hands and Voices.

Other activities for the new contract year include development of additional parent materials, training for audiologists, and training for early intervention providers. The provider training will be offered in two 3-day sessions on the IN-SITE model curriculum of home intervention for infant, toddler and preschool aged children who are dual sensory impaired (hearing/vision) and have multiple disabilities. This training will be coordinated by the Virginia Deaf/Blind Project.

Report on Health and Human Services Initiative

Frank Aiello spoke on the progress of the National Initiative on Effective Intervention Services for Infants and Young Children with Hearing Loss. Efforts have continued to work through the political process. There was a meeting of the Office On Disability Constituent Expert Working Group on August 13 to review the recommendations for legislation needed to address the issues of infants and young people with hearing loss. The progress of each recommendation was discussed and strategies formulated for a discussion with the federal partners at the August 14th meeting. At the meeting on August 14 at Health and Human Services (HHS), educational, health care, and research recommendations were reviewed. The federal agency partners and Surgeon General Kenneth Moritsugu promised to shift resources if necessary to provide support on closing the gaps in services. Dr. Margaret Giannini, Office on Disability at HHS, is leading this initiative.

Report from Follow-Up Coordinator

Ruth Frierson updated the committee on the new brochure for parents that will not only be provided to

hospitals but will be placed in the physician offices, health clinics, birthing centers, and health departments. It is intended to convey information about newborn hearing screening, stress the need for early identification of hearing loss and the need for communication with the child's primary medical care provider. The brochure also contains developmental milestones. Once it has received final VDH approval, it will be translated into Spanish, printed, and distributed.

There has been a decrease in the number of children in the database with an unknown PCP due to Loucendia Lambert's efforts to obtain this information. The next step is to educate hospitals regarding the importance of identifying the PCP rather than reporting "unknown."

Report from Surveillance and Evaluation Coordinator

Susan Lau reported that the 2005 Annual Report will be printed and distributed next week. In addition, the annual status report will be sent to hospital CEOs in the next month also based on 2005 data. The data comparing all hospitals was reviewed with the group.

There were 276 parent surveys (in English and Spanish) mailed last Friday to parents of children identified with hearing loss and reported to VDH EHDI. Responses are already coming in. Results will be analyzed and a report written. The information will be shared with hospitals and audiologists and will be used to make improvements in the program.

Re-certification/registration forms were mailed out to audiologists several months ago. Acknowledgement letters have been delayed until staff can contact previously approved locations that did not submit this year.

Eight hospitals were sent certificates of excellence for 2005. There was significant improvement in reporting, both timeliness and accuracy, over previous years. The April-May-June 2006 quarter showed the highest percentage ever of hospitals reporting on time; the average reporting time has decreased to less than 11 days. The requirement is to report within one week of discharge.

Susan Lau will begin to schedule record reviews with hospitals. The purpose is two-fold. The first is to audit hospital reporting; the second, to maintain personal contact with hospital staff.

Susan Lau asked for suggestions from the group regarding data to be included in the next annual report. These suggestions can be communicated to her at any time.

Discussion

Craig Derkay asked if military hospitals are included in the VDH reporting. Susan Lau informed him that their data are included; however, they do not get a status report the way other hospitals do because they are not required to report to VDH. Langley and Portsmouth do a good job of screening and reporting. Dewitt is doing better. Craig Derkay stated that the military staff in charge of the hospital would be interested in the information and suggested that they be sent a status report the same as other hospitals.

Craig Derkay asked if data from Children's Hospital of The King's Daughters could be reported separately since there are technically no births there, it is all intensive and special care services, and it seems to skew the report.

Craig Derkay also expressed his concern that children were being "lost" when they moved from Neonatal Intensive Care Unit (NICU) to hospital transitional care/step down units. Some children can remain in hospital NICU or other nurseries for many months. It was suggested that recommendations regarding when to screen hearing be included in the hospital protocols. Even though hearing screening is not required to be reported until after discharge, it could be recommended that when babies are transferred out of the NICU into another nursery their hearing status must be checked within an "appropriate time frame." Bob Boyle

suggested that there needed to be a definition of a “appropriate” that relates to the age of the child. Fredia Helbert suggested that data from hospitals with a NICU be shown separately from the other hospitals.

The group suggested that there be a “mean” shown at the bottom of the hospital data chart so hospitals can see how they compare to others and to the requirements.

Loucendia Lambert asked about the status of having deaf membership on the Advisory Committee. Pat Dewey reported that it had been a number of years since there had been a person who is deaf or hard of hearing as part of the group. Suggestions for persons to serve should be submitted to Pat Dewey. Members of the Advisory are appointed by the Commissioner of Health.

Craig Derkay asked whether children of migrant workers and children in foster care are tracked and receive services. Ruth Frierson stated that all children reported by hospitals and audiologists are tracked until the family moves and no alternative contact information can be found. If the hospital reports the contact information for the agency handling foster care or the foster family, VDH sends a letter to them. Adoptions are handled in the same way.

Next Meeting

The next meeting will be held on December 8, 2006 at the offices of the Virginia Hospital and Healthcare Association in Glen Allen. At that time, the group will set the meeting dates for 2007.